

Current Status of Research That Dietary Modification Can Benefit The Majority Of Children on the Autism Spectrum

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Background

"Based on reports from caregivers, case studies, and observation of patients with schizophrenia and children with severe behavioral disorders, Dr. FC Dohan hypothesized, in 1960s and 70s, that gluten and dairy foods might worsen these behaviors. He noted that in many cases, a restricted diet could lead to significant improvement or recovery from these disorders. For several years, the biochemical explanation for this phenomenon remained unclear. However, several other studies seemed to bear out this observation, and in 1981, using more advanced laboratory technology, Dr. Karl Reichelt, Director of Clinical Chemistry for the Department of Pediatric Research at the Rikshospitalet (National Hospital) in Oslo, Norway, found and reported abnormal peptides in the urine of schizophrenics and autistics. Peptides are pieces of proteins that are not completely broken down into individual amino acids. Dr. Reichelt has observed that these peptides, which are 4 or 5 or 6 amino acids long, have sequences that match those of opioid peptides (casomorphin and gliadomorphin). The known dietary sources of these opiate peptides are casein (from milk) and gliadin or gluten (from cereal grains). He has since conducted several studies examining this finding, as have several other researchers, including Paul Shattock at the University of Sunderland in England, Dr. Robert Cade at the University of Florida, Gainesville, and Dr. Alan Friedman, of Johnson and Johnson Ortho Clinical Diagnostics. The best evidence for this correlation lies in the thousands of case reports of improvement or recovery of children with autism on this diet. However, responsible physicians who have taken the time to review these studies must agree that there is, indeed, significant scientific evidence to support a trial period of careful elimination of these proteins from the diet of children on the autistic spectrum."

Source: [Autism Network For Dietary Intervention](#)

Below are sections relating to studies looking at dietary intervention and parent surveys that are the source of the anecdotal evidence being ignored by many sections of the medical community. In fairness there are some practitioners that are coming on board. Professor Kerry Phelps on the Sunrise program acknowledged that there is sufficient anecdotal evidence and dietary modification is a **low risk strategy**.

The Dietary Studies

On May 29 –30, 2008, a multidisciplinary panel of 28 experts convened in Boston, Massachusetts, to review and discuss gastrointestinal aspects of ASDs. They published a consensus report with 23 recommendations.

Evaluation, Diagnosis, and Treatment of Gastrointestinal Disorders in Individuals with ASDs: A Consensus Report.

[Pediatrics 2010;125;S1-S18](#)

Abstract

Autism spectrum disorders (ASDs) are common and clinically heterogeneous neurodevelopmental disorders. Gastrointestinal disorders and associated symptoms are commonly reported in individuals with ASDs, but key issues such as the prevalence and best treatment of these conditions are incompletely understood. A central difficulty in recognizing and characterizing gastrointestinal dysfunction with ASDs is the communication difficulties experienced by many affected individuals. A multidisciplinary panel reviewed the medical literature with the aim of generating evidence-based recommendations for diagnostic evaluation and management of gastrointestinal problems in this patient population. The panel concluded that evidence-based recommendations are not yet available. *The consensus expert opinion of the panel was that individuals with ASDs deserve the same thoroughness and standard of care in the diagnostic workup and treatment of gastrointestinal concerns as should occur for patients without ASDs. Care providers should be aware that problem behavior in patients with ASDs may be the primary or sole symptom of the underlying medical condition, including some gastrointestinal disorders. For these patients, integration of behavioral and medical care may be most beneficial.* Priorities for future research are identified to advance our understanding and management of gastrointestinal disorders in persons with ASDs.

Comment

There were 23 Consensus Statements contained in the report. Five statements pertaining to diet were included and are listed below.

Statement 9

Pediatricians and other primary care providers should be alert to potential nutritional problems in patients with ASDs. Evaluation by a nutritionist who is familiar with nutrition support for individuals with ASDs is recommended if caregivers raise concern about the patient's diet or if the patient exhibits selectivity of intake or is on a restricted diet.

Statement 11

Anecdotal reports have suggested that there may be a subgroup of individuals with ASDs who respond to dietary intervention. Additional data are needed before pediatricians and other professionals can recommend specific dietary modifications.

Statement 12

Available research data do not support the use of a casein-free diet, a gluten-free diet, or combined gluten-free, casein-free (GFCF) diet as a primary treatment for individuals with ASDs.

Statement 13

For patients with ASDs, a detailed history should be obtained to identify potential associations between allergen exposure and gastrointestinal and/or behavioral symptoms.

Statement 15

For patients with ASDs, a detailed history (including personal history of allergic disease, dietary history, and family history) and physical examination should be performed to accurately identify potential comorbid allergic disease.

Comment

The recommendations on dietary modification are based on **one study** which was a proper scientifically conducted double blind study, which the committee could accept for consideration. The study abstract is reproduced below.

The Gluten-Free, Casein-Free Diet In Autism: Results of A Preliminary Double Blind Clinical Trial

Journal of Autism and Developmental Disorders, Vol. 36, No. 3, April 2006

Abstract

This study tested the efficacy of a gluten-free and casein-free (GFCF) diet in treating autism using a randomized, double blind repeated measures crossover design. The sample included 15 children aged 2–16 years with autism spectrum disorder. Data on autistic symptoms and urinary peptide levels were collected in the subjects' homes over the 12 weeks that they were on the diet. **Group data indicated no statistically significant findings even though several parents reported improvement in their children.** Although preliminary, this study demonstrates how a controlled clinical trial of the GFCF diet can be conducted, and suggests directions for future research.

Comment:

If you read the full study, there are some very interesting points that quite interestingly did not have more emphasis in the abstract, which is what most people would only have access to. Included in the report are these two comments:

“...parents of seven children reported that there were **marked improvements in their child's language, decreased hyperactivity and decreased tantrums.** Further, **parents of nine children decided to keep their children on the GFCF diet** even though there was no empirical support for continuing.”

Comment: As a medical Scientist I find it amazing that more than half of the parents in the study group decided "to keep their children on a GFCF diet". Anyone who has a child on the spectrum knows that, as parents, they are under more stress than those with neurotypical children. **Therefore it is amazing that 9 out of 13 parents (69%) decided to keep their children on a GFCF diet.** Why would busy, stressed parents make the additional effort to take on a GFCF diet if they did not feel it made a difference? The 69% of parents in this study that continued with the GFCF diet is in line with the anecdotal evidence from [parent surveys](#). And further

“Also interesting were the unsolicited reports of one teacher and one respite worker who claimed to observe language and behaviour improvements in two of the children.”

Comment: So apart from the parents, there were two other independent reports of improvement in two of the children. **I am unaware of any other intervention that can produce such rapid improvements in behaviour, speech or gastrointestinal symptoms in our children, within 6 weeks!**

Further as a proper double blind study, the child's regular diet was replicated to be gluten and casein free. Therefore to be able to do such studies, food technologists need to replicate a child's normal diet and reproduce the same foods, except that they do not contain gluten or casein. Knowing that many children are also sensitive to salicylates, amines and or glutamates, how can this be achieved without having to resort to artificial colours and flavour enhancers that children are known to also react to? Frankly I am amazed that the children in the study actually did so well!

Other Dietary Studies

There are more studies being published in favour of dietary intervention in peer reviewed journals in recent years. Busy pediatricians, psychiatrists, psychologists, nutritionists and other medical professionals are often not aware of these studies or fail to read more than just the abstracts of the studies. Of note are journals of nutrition and dietetics that are least supportive of dietary modification in autism. There is definitely a subgroup of children that respond very favourably to a change in diet. The Royal Prince Alfred Hospital - Allergy Elimination Clinic appears to be going against this trend.

Whiteley P, et al. The ScanBrit randomised, controlled, single-blind study of a gluten- and casein-free dietary intervention for children with autism spectrum disorders. *Nutr Neurosci.* 2010 Apr;13(2):87-100.

Abstract

There is increasing interest in the use of gluten- and casein-free diets for children with autism spectrum disorders (ASDs). We report results from a two-stage, 24-month, randomised, controlled trial incorporating an adaptive 'catch-up' design and interim analysis. Stage 1 of the

trial saw 72 Danish children (aged 4 years to 10 years 11 months) assigned to diet (A) or non-diet (B) groups by stratified randomisation. Autism Diagnostic Observation Schedule (ADOS) and the Gilliam Autism Rating Scale (GARS) were used to assess core autism behaviours, Vineland Adaptive Behaviour Scales (VABS) to ascertain developmental level, and Attention-Deficit Hyperactivity Disorder - IV scale (ADHD-IV) to determine inattention and hyperactivity. Participants were tested at baseline, 8, and 12 months. ***Based on per protocol repeated measures analysis, data for 26 diet children and 29 controls were available at 12 months. At this point, there was a significant improvement to mean diet group scores (time*treatment interaction) on sub-domains of ADOS, GARS and ADHD-IV measures. Surpassing of predefined statistical thresholds as evidence of improvement in group A at 12 months sanctioned the re-assignment of group B participants to active dietary treatment.*** Stage 2 data for 18 group A and 17 group B participants were available at 24 months. Multiple scenario analysis based on inter- and intra-group comparisons showed some evidence of sustained clinical group improvements although possibly indicative of a plateau effect for intervention. Our results suggest that dietary intervention may positively affect developmental outcome for some children diagnosed with ASD. In the absence of a placebo condition to the current investigation, we are, however, unable to disqualify potential effects derived from intervention outside of dietary changes. Further studies are required to ascertain potential best- and non-responders to intervention.

Genius SJ, Bouchard TP. Celiac disease presenting as autism. J Child Neurol. 2010 Jan;25(1):114-9. Epub 2009 Jun 29.

Abstract

Gluten-restricted diets have become increasingly popular among parents seeking treatment for children diagnosed with autism. Some of the reported response to celiac diets in children with autism may be related to amelioration of nutritional deficiency resulting from undiagnosed gluten sensitivity and consequent malabsorption. A case is presented of a 5-year-old boy diagnosed with severe autism at a specialty clinic for autistic spectrum disorders. After initial investigation suggested underlying celiac disease and varied nutrient deficiencies, a gluten-free diet was instituted along with dietary and supplemental measures to secure nutritional sufficiency. ***The patient's gastrointestinal symptoms rapidly resolved, and signs and symptoms suggestive of autism progressively abated.*** This case is an example of a common malabsorption syndrome associated with central nervous system dysfunction and suggests that in some contexts, nutritional deficiency may be a determinant of developmental delay. It is recommended that all children with neurodevelopmental problems be assessed for nutritional deficiency and malabsorption syndromes.

Hsu CL, Lin CY, Chen CL, Wang CM, Wong MK. **The effects of a gluten and casein-free diet in children with autism: a case report.** *Chang Gung Med J.* 2009 Jul-Aug;32(4):459-65.

Abstract

A boy with autism, growth and developmental retardation was brought to our clinic. He was diagnosed with CHARGE syndrome. Subsequently, various therapies were introduced when he was 5 months old yet the developmental delays persisted. Gastrointestinal problems such as frequent post-prandial vomiting and severe constipation were noted as well. At the age of 42 months, the boy was subjected to a gluten and casein-free diet. Soybean milk and rice were substituted for cow's milk, bread and noodles. *After 2.5 months, interpersonal relations including eye to eye contact and verbal communication improved. At 5.5 months the boy was capable of playing and sharing toys with his sibling and other children, behavior noted to be closer to that of an unaffected child.* In addition, the decreased frequency of postprandial vomiting led to a significant increment in body weight, body height (from below the third percentile to the tenth percentile) and vitality after 11 months on the diet. In view of the lack of consensus on the benefits of dietary intervention in patients with autism, *we are suggesting an adjuvant therapy that is simple, safe and economical.* In addition, the therapy may be more feasible in Taiwan as opposed to western countries because of cultural factors such as dietary preference and product availability.

Srinivasan P. **A review of dietary interventions in autism.** *Ann Clin Psychiatry.* 2009 Oct-Dec;21(4):237-47.

Abstract

BACKGROUND: *Anecdotal reports and parent surveys have shown evidence that dietary interventions have had some success in ameliorating the symptoms of autism.*

METHODS: In this paper, key findings that prompt a dietary intervention strategy are reviewed and popular intervention diets are described.

RESULTS: There is a significant body of literature pertinent to dietary interventions in autism from the perspectives of gastroenterology, immunology, and excitotoxicity. *Some articles report benefits to patients on standardized rating scales.*

CONCLUSIONS: This article presents a survey of the literature related to dietary interventions studied in the context of autism as well as various hypotheses on the rationale for dietary interventions. *Patients or caregivers increasingly are attempting such interventions.* Further studies are needed to establish the efficacy of these diets, the patients who would best benefit from diets, the mechanism of action, and the role of diets in addition

to other treatments.

Reichelt KL, Knivsberg AM. The possibility and probability of a gut-to-brain connection in autism. *Ann Clin Psychiatry*. 2009 Oct-Dec;21(4):205-11.

Abstract

BACKGROUND: We have shown that urine peptide increase is found in autism, and that some of these peptides have a dietary origin. To be explanatory for the disease process, a dietary effect on the brain must be shown to be possible and probable.

METHODS: Diagnosis was based on DSM-III and DSM-IV criteria. We ran first morning urine samples equivalent to 250 nm creatinine on high-performance liquid chromatography (HPLC) reversed phase C18 columns using trifluoroacetic acid acetonitrile gradients. The elution patterns were registered using 215 nm absorption for largely peptide bonds, 280 nm for aromatic groups, and 325 nm for indolyl components. We referred to a series of published ability tests, including Raven's Progressive Matrices and the Illinois Test of Psycholinguistic Ability, which were administered before and after dietary intervention. The literature was also reviewed to find evidence of a gut-to-brain connection.

RESULTS: In autistic syndromes, we can show marked increases in UV 215-absorbing material eluting after hippuric acid that are mostly peptides. We also show highly significant decreases after introducing a gluten- and casein-free diet with a duration of more than 1 year. *We refer to previously published studies showing improvement in children on this diet who were followed for 4 years and a pairwise matched, randomly assigned study with highly significant changes. The literature shows abundant data pointing to the importance of a gut-to-brain connection.*

CONCLUSIONS: *An effect of diet on excreted compounds and behavior has been found.* A gut-to-brain axis is both possible and probable.

Elder JH. [The gluten-free, casein-free diet in autism: an overview with clinical implications.](#) *Nutr Clin Pract*.2008 Dec-2009 Jan;23(6):583-8.

Abstract

The prevalence of classic autism and autism spectrum disorder (ASD) appears to be on the rise, and to date, there remains no clear etiology or cure. Out of desperation, many families are turning to new therapies and interventions discovered through various media sources and anecdotal reports from other parents. Unfortunately, many of these newer, well-publicized interventions have little empirical support. One of the most popular yet currently scientifically unproven interventions for ASD is the gluten-free, casein-free (GFCF) diet. *Clinicians working with families of individuals with ASD are often asked for advice and find themselves unable to offer the most up-to-date and scientifically credible information.* This article provides an overview of ASD and the GFCF diet, a summary and critique of current

research findings, recommendations for future research, and practical advice for families to use in deciding if a trial of the GFCF diet is in the best interest of their child and family.

Goday P. *Whey watchers and wheat watchers: the case against gluten and casein in autism.* Nutr Clin Pract. 2008 Dec-2009 Jan;23(6):581-2. No abstract available

Comment: This is an invited commentary to the above journal article by Elder, "The Gluten-free, casein-free diet in autism: an overview with clinical implications."

Hjiej H, Doyen C, Couprie C, Kaye K, Contejean Y. *[Substitutive and dietetic approaches in childhood autistic disorder: interests and limits] [Article in French]. Encephale. 2008 Oct;34(5):496-503. Epub 2008 Mar 4.*

Abstract

INTRODUCTION: Autism is a developmental disorder that requires specialized therapeutic approaches. Influenced by various theoretical hypotheses, therapeutic programs are typically structured on a psychodynamic, biological or educative basis. Presently, educational strategies are recommended in the treatment of autism, without excluding other approaches when they are necessary. *Some authors recommend dietetic or complementary approaches to the treatment of autism, which often stimulates great interest in the parents but also provokes controversy for professionals. Nevertheless, professionals must be informed about this approach because parents are actively in demand of it.* **LITERATURE FINDINGS:** First of all, enzymatic disorders and metabolic errors are those most frequently evoked in the literature. The well-known phenylalanine hydroxylase deficit responsible for phenylketonuria has been described as being associated with autism. In this case, adapted diet prevents mental retardation and autistic symptoms. Some enzymatic errors are also corrected by supplementation with uridine or ribose for example, but these supplementations are the responsibility of specialized medical teams in the domain of neurology and cannot be applied by parents alone. Secondly, increased opioid activity due to an excess of peptides is also supposed to be at the origin of some autistic symptoms. *Gluten-free or casein-free diets have thus been tested in controlled studies, with contradictory results. With such diets, some studies show symptom regression but others report negative side effects, essentially protein malnutrition.* Methodological bias, small sample sizes, the use of various diagnostic criteria or heterogeneity of evaluation interfere with data analysis and interpretation, which prompted professionals to be cautious with such diets. The third hypothesis emphasized in the literature is the amino acid domain. *Some autistic children lack some amino acids* such as glutamic or aspartic acids for example and this deficiency would create autistic symptoms. However, for some authors, these deficits are attributed to nutritional deficits caused by the food selectivity of children. A fourth hypothesis concerning metabolic implication in autism is the suspicion that a *food allergy phenomenon* could interfere with development, and it has been observed that Ig levels are higher in autistic children than in control children. Autistic children with a positive reaction to food Ig would have a more favourable outcome with diet excluding some kinds of food; but most of those diets are drastic and ethically debatable. Fifth, glucidic catabolism could be deleterious with an excess of ketonic products that will initiate comitial

seizures. Few studies with ketogenic diet have been conducted but, as it has been described with epileptic subjects, those diets would diminish autistic symptoms. Not enough studies have been conducted that would allow one to draw any firm conclusions. The sixth hypothesis is linked with *vitamin deficiencies* that are a notably important area of research in the treatment of autism. Vitamin B12 or B6 deficiencies have been studied in several articles, and many of them were controlled studies. French teams also emphasize an interest in supplementation with B12 or B6. The two last hypotheses concern auto-immune patterns and the toxic effects of heavy metals like mercury. There is a paucity of methodologically satisfying studies that support these two hypotheses and diet recommendations. Following these assumptions, *some dietetic approaches have been recommended, even though the methodological aspects of supporting studies are poor. The most famous diet is the gluten-free and/or casein-free diet. Only two controlled studies attracted our attention. Even if for some autistic children such a diet was positive, for others, gluten-free or casein-free diets were poorly tolerated and, for some authors, not without considerable side effects*, the more prejudicial of which was the Kwashiorkor risk. Ketogenic diets have been studied in one non controlled study, but even if positive results have been noted by the authors, the ketogenic diet is very restricting and the long term effects have not been evaluated. Vitamin supplementation is the one and only diet domain where there have been many repeated and placebo-controlled studies. Side effects are rare and mild even if high doses of vitamin B6 are advocated in these studies. In total, as evoked by Rimland, 11 controlled placebo-blind studies have been conducted and 50% of autistic children with this supplementation had improved autistic signs. However, these results still remain debated. Finally, more rarely, enzymatic abnormalities need specific diets which have some positive consequences, but such diets could not be applied by parents alone and are the responsibility of specialized teams. *For discussion purposes we can emphasize that, in spite of the amount of studies concerning the effects of specialized diets, few are methodologically satisfying.* We cannot ignore that some side effects are possible with such approaches and parents need to be informed of them. Some are even potentially serious, such as diets with metal chelators. In spite of those results, vitamin supplementation seems to be the only one that some specialized teams in autism could apply, always with parent agreement. In conclusion, within this scientific field, studies on eating habits of autistic children should be conducted because of their food selectivity or avoidance.

Millward C, Ferriter M, Calver S, Connell-Jones G. Gluten- and casein-free diets for autistic spectrum disorder. Cochrane Database Syst Rev. 2008 Apr 16;(2):CD003498.

Abstract

BACKGROUND: It has been suggested that peptides from gluten and casein may have a role in the origins of autism and that the physiology and psychology of autism might be explained by excessive opioid activity linked to these peptides. Research has reported abnormal levels of peptides in the urine and cerebrospinal fluid of people with autism.

OBJECTIVES: To determine the efficacy of gluten and/or casein free diets as an intervention to improve behaviour, cognitive and social functioning in individuals with autism.

SEARCH STRATEGY: The following electronic databases were searched: CENTRAL(The Cochrane Library Issue 2, 2007), MEDLINE (1966 to April 2007), PsycINFO (1971 to April 2007), EMBASE (1974 to April 2007), CINAHL (1982 to April 2007), ERIC (1965 to 2007), LILACS (1982 to April 2007), and the National Research register 2007 (Issue1). Review bibliographies were also examined to identify potential trials.

SELECTION CRITERIA: All randomised controlled trials (RCT) involving programmes which eliminated gluten, casein or both gluten and casein from the diets of individuals diagnosed with an autistic spectrum disorder.

DATA COLLECTION AND ANALYSIS: Abstracts of studies identified in searches of electronic databases were assessed to determine inclusion by two independent authors. The included trials did not share common outcome measures and therefore no meta-analysis was possible. Data are presented in narrative form.

MAIN RESULTS: *Two small RCTs were identified* (n = 35). No meta-analysis was possible. *There were only three significant treatment effects in favour of the diet intervention: overall autistic traits*, mean difference (MD) = -5.60 (95% CI -9.02 to -2.18), z = 3.21, p=0.001 (Knivsberg 2002) ; *social isolation*, MD = -3.20 (95% CI -5.20 to -1.20), z = 3.14, p = 0.002) *and overall ability to communicate and interact*, MD = 1.70 (95% CI 0.50 to 2.90), z = 2.77, p = 0.006) (Knivsberg 2003). In addition three outcomes showed no significant difference between the treatment and control group and we were unable to calculate mean differences for ten outcomes because the data were skewed. No outcomes were reported for disbenefits including harms.

AUTHORS' CONCLUSIONS: Research has shown of high rates of use of complementary and alternative therapies (CAM) for children with autism including gluten and/or casein exclusion diets. Current evidence for efficacy of these diets is poor. Large scale, good quality randomised controlled trials are needed.

Comment: The two studies referred to in the above report were:

Elder JH, Shanker M, Shuster J, Theriaque D, Burns S, Sherrill L. The gluten-free, casein-free diet in autism: Results of a preliminary double blind clinical trial. *Journal of Autism and Developmental Disorders* 2006;36(3):413–20.

Knivsberg A-M, Reichelt KL, Høien T, Nødland M. A randomised, controlled study of dietary intervention in autistic syndromes. *Nutritional Neuroscience* 2002;5(4):251–61.

Knivsberg A-M, Reichelt KL, Høien T, Nødland M. Effect of dietary intervention on autistic behavior. *Focus on Autism and Other Developmental Disabilities* 2003;18(4):247–56.

Curtis LT, Patel K. Nutritional and environmental approaches to preventing and treating autism and attention deficit hyperactivity disorder (ADHD): a review. *J Altern Complement Med.* 2008 Jan-Feb;14(1):79-85.

Lakhan SE, et al. **Nutritional therapies for mental disorders.** *Nutr J.* 2008 Jan 21;7:2.

Angley M, Semple S, Hewton C, Paterson F. **Children and autism--Part 2--management with complementary medicines and dietary interventions.** *Aust Fam Physician.* 2007 Oct;36(10):827-30.

Abstract

BACKGROUND: Complementary and alternative medicines (CAMs) and dietary interventions are widely used in the management of autistic disorders as *pharmacological treatments offered by mainstream medicine are limited and often associated with significant adverse effects.*

OBJECTIVE: In this article, the rationale, safety and efficacy of a range of CAMs and dietary interventions used in the management of autistic disorders are discussed.

DISCUSSION: Despite many anecdotal reports supporting the efficacy of CAMs, evidence for their use in autistic disorders is either unclear or conflicting, and available data comes from a limited number of small studies. Large randomised controlled trials have not yet been conducted to examine efficacy in this population. Although most interventions are associated with only mild adverse effects, there is a lack of long term safety data. General practitioners need to be aware that the use of CAMs in autism is not risk free and often lacks sound clinical evidence. *On the other hand, there may be subtle benefits to the child, especially if interventions are coupled with intensive behavioural and/or educational intervention.*

Elder JH, Shankar M, Shuster J, Theriaque D, Burns S, Sherrill L. **The gluten-free, casein-free diet in autism: results of a preliminary double blind clinical trial.** *J Autism Dev Disord.* 2006 Apr;36(3):413-20.

Abstract

This study tested the efficacy of a gluten-free and casein-free (GFCF) diet in treating autism using a randomized, double blind repeated measures crossover design. The sample included 15 children aged 2-16 years with autism spectrum disorder. Data on autistic symptoms and urinary peptide levels were collected in the subjects' homes over the 12 weeks that they were on the diet. *Group data indicated no statistically significant findings even though several parents reported improvement in their children.* Although preliminary, this study demonstrates how a controlled clinical trial of the GFCF diet can be conducted, and suggests directions for future research.

Comment: Additional observations on the content of this study are discussed above.

See: [Evaluation, Diagnosis, and Treatment of Gastrointestinal Disorders in Individuals With ASDs: A Consensus Report](#)

Christison GW, Ivany K. **Elimination diets in autism spectrum disorders: any wheat**

amidst the chaff? *J Dev Behav Pediatr.* 2006 Apr;27(2 Suppl):S162-71.

Knivsberg AM, et al. *A randomised, controlled study of dietary intervention in autistic syndromes.* *Nutr Neurosci.* 2002 Sep;5(4).

Abstract

Impaired social interaction, communication and imaginative skills characterize autistic syndromes. In these syndromes urinary peptide abnormalities, derived from gluten, gliadin, and casein, are reported. They reflect processes with opioid effect. The aim of this single blind study was to evaluate effect of gluten and casein-free diet for children with autistic syndromes and urinary peptide abnormalities. A randomly selected diet and control group with 10 children in each group participated. Observations and tests were done before and after a period of 1 year. *The development for the group of children on diet was significantly better than for the controls.*

Knivsberg AM, et al. *Reports on dietary intervention in autistic disorders.* *Nutr Neurosci.* 2001;4(1):25-37.

Abstract

Autism is a developmental disorder for which no cure currently exists. *Gluten and/or casein free diet has been implemented to reduce autistic behaviour, in addition to special education, since early in the eighties.* Over the last twelve years various studies on this dietary intervention have been published in addition to anecdotal, parental reports. *The scientific studies include both groups of participants as well as single cases, and beneficial results are reported in all, but one study.* While some studies are based on urinary peptide abnormalities, others are not. *The reported results are, however, more or less identical; reduction of autistic behaviour, increased social and communicative skills, and reappearance of autistic traits after the diet has been broken.*

Ashkenazi A, Levin S, Krasilowsky D. *Gluten and autism.* *Lancet.* 1980 Jan 19;1(8160):157.

Autism Research Institute - Parent Survey

Special Diets	Got Worse	No Effect	Got Better	Better: Worse
Candida diet	3%	39%	58%	21:1
Feingold Diet	2%	40%	58%	26:1
Gluten/ Casein	3%	28%	69%	24:1
Free Diet				
Low Oxalate	7%	43%	50%	6.8:1
Removed Chocolate	2%	46%	52%	29:1
Removed Eggs	2%	53%	45%	20:1
Removed Milk	2%	44%	55%	32:1
Products/ Dairy				
Removed Sugar	2%	46%	52%	27:1
Removed Wheat	2%	43%	55%	30:1
Rotation Diet	2%	43%	50%	23:1
Specific Carbohydrate Diet	7%	22%	71%	10:1

Source: [ARI Treatment Ratings - Autism](#)

Comment

Each year that this survey is updated, the percentage of parents that see beneficial effects in their children continues to increase. This may be that newer parents have the benefit of learning from experienced parents that have implemented the diet and that the range of gluten free products are increasing and becoming more widely available.

Australian and NZ Survey

Type of Diet	No Apparent Effect After 1 Month	Some Apparent Effect After 1 Month	Some Effect Within 1-4 Weeks	Immediate Effect (within 1 week)
Casein Free (CF)	21.7%	20.5%	24.1%	33.7%
Gluten Free (GF)	20.2%	33.3%	22.6%	23.8%
GF/CF	21.9%	19.8%	30.2%	28.1%
GF/CF Soy free (SF)	17.9%	17.9%	23.9%	40.3%
Chocolate Removed	27.0%	13.5%	21.6%	37.8%
Eggs Removed	48.3%	13.8%	13.8%	24.1%
Sugar Removed	19.3%	14.0%	31.6%	35.1%
A2 Milk	54.1%	16.2%	5.4%	24.3%
Non-Allergenic	12.5%	20.8%	25.0%	41.7%
Salicylate Free	19.4%	13.9%	30.6%	36.1%

Source: [Australian Biomedical Parent Survey](#)

Comment

What is rather amazing with this survey is the percentage of parents that saw a beneficial effect ***within one week*** of implementing the diet. Overall if we look at the ***benefits for more than a month, 82.1% of parents found some beneficial effect for their child*** when gluten/casein/soy are removed from the diet. This is anecdotal evidence that cannot be ignored.

Royal Prince Alfred Hospital - Allergy Elimination Clinic. Student Studies

A Whole New World: Diet Modification in Children with ASD. An in-depth qualitative study

Andrea Mae (Andee) Alano

Master of Nutrition and Dietetics, The University of Sydney. October 2006.

Abstract

Introduction: There has been considerable interest on the effect of diet on individuals with ASD, but in the absence of large randomly controlled clinical trials, diet modification is still classified as a complementary and alternative medical (CAM) therapy. The implementation of a modified diet among children with ASD has been increasing, however at present there is minimal research on the factors involved in the management of such diets.

Aims: To investigate parental beliefs regarding ASD and diet. Particularly, to explore the experiences, long term outcomes, and problems that may come about with diet modification, as well as to discover parents' views on what is needed to manage these diet modifications.

Methods: This qualitative study used in-depth interviews as the primary tool for data collection. To achieve the aims of the study, topics covered in the interviews included the child's current or previous diet/s, the parent's sources of information and support, any lifestyle changes made, and their opinions on what was necessary to successfully manage a modified diet. All interviews were recorded and transcribed verbatim. Key concepts and themes were identified from the transcripts and a framework for coding the data was developed. Analysis was done using qualitative analysis techniques.

Results: A total of 20 in-depth interviews with parents of children with ASD were conducted. It was found that parents modified their child's diet to resolve some behaviour issues (65%) and GI issues (50%). The majority of parents (80%) reported noticing positive improvements in their children, particularly in behaviour and communication. It was reported that shopping and cooking habits required the most changes. In addition, social functions, an overall lack of support, and their child's food selectivity were the biggest difficulties encountered. Parents also reported that being organized and perseverance were the main means used to successfully implement a diet.

Conclusion: ***This study has established that parents have found diet modification as a challenging experience to take on, however due to the observed improvements in their***

children, most have found that the benefits outweigh the difficulties. Parents believe that an increase in support systems (both emotional and educational) will be beneficial in the future management of a modified diet.

Dietary Modification in the Management of Autistic Spectrum Disorders (ASD). A non-randomised Intervention Study.

Elizabeth Parker

Master of Science (Nutrition and Dietetics), University of Wollongong. Link to [full pdf](#).

Abstract

In the absence of a known cause or cure for autism, attention has been focused on strategies to treat the associated symptoms. Dietary modification has emerged as a possible ‘alternative treatment’ for autism and related spectrum disorders. It has been suspected that autistic children may experience increased food sensitivity to a wide range of foods, and dietary exclusion of suspect foods may result in behavioural improvements and decreased gastrointestinal symptoms. The gluten- and casein-free diet is one such diet that has gained strong parental interest and support, despite the lack of strong large-scale evidence to support its effectiveness at improving behaviour. *The primary aim of this study was to investigate the effectiveness of dietary modification at reducing behavioural and health problems associated with autism.* This follow-up study was conducted by questionnaire, with parent rated scores of specified autistic traits and symptoms compared with results obtained prior to dietary modification. Mean scores of parametric data obtained were compared using the Paired *t*-test and Independent *t*-test, and non-parametric data was compared using the Wilcoxon Sign-Ranked Test and Mann-Whitney U test. *Significant improvements ($p < 0.05$) were observed in maladaptive behaviours, sleep disturbances and gastrointestinal symptoms in the Diet Group, particularly those undertaking the gluten and casein free diet combined with low chemical.* No significant changes were found in the Control Group. *Overall, increased food sensitivity appears to affect a sub-population of autistic children, and dietary modification may help aid in the management of ASD, resulting in improvements in behaviour and gastrointestinal symptoms.*

Food Intolerance and Dietary Modification in Children with Autism Spectrum Disorder (ASD)

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Abstract

Background: Autistic Spectrum Disorder (ASD) encompasses a range of developmental disorders, characterised by a triad of symptoms including impaired social interaction skills, communication skills and symbolic or imaginative play. The aetiology of ASD is complex and not yet well understood. Amongst others, diet is one factor implicated as potentially causative in ASD. Gluten-free and casein-free diets have been reported to result in

improvements in the symptoms of ASD. Absence of these dietary proteins alone cannot be conclusively said to be the cause of these improvements, as removing foods containing casein and gluten from the diet is also likely to result in an altered intake of other food chemicals. *It appears that parents turn away from conventional medical practitioners and seek advice on dietary modification from alternate sources, possibly because of a lack of support from the medical profession.*

Objective: To document the food intolerances and symptoms observed in children with ASD, as well as the efficacy and sustainability of dietary modification in those children with ASD who have food intolerances.

Design: Children with ASD were compared with milk intolerant children and children with neither ASD nor food intolerance in a questionnaire based study. Issues examined include symptoms potentially related to food intolerance, any history of adverse reactions to foods or dietary modification and the impact of the children on their families.

Results: The children with ASD exhibited a number of behavioural and gastrointestinal symptoms, which may relate to food intolerance. These symptoms generally began early in life, before abnormal/ASD behaviours and persisted into the present in many cases. *Dietary modification had taken place in 100% of the children with ASD and was currently in place for 87.50%. A range of foods were reported as responsible for adverse reactions and many different symptoms were improved with dietary modification.*

Conclusion: A group of children with ASD exhibiting symptoms of food intolerance to a range of foods has been described. Dietary modification was generally effective and sustainable in these children. Continued research is needed to further elucidate the role and prevalence of food intolerance in children with ASD.

The Case for Anecdotal Evidence

Medical and other professionals say that there is only anecdotal evidence that dietary modification is beneficial for children on the autism spectrum and there are no clinical studies that support dietary modification. May I remind these professionals that some of the major medical advances of our time began with an astute individual being brave enough to put forward a concept that the medical community at the time did not accept. Only many years later were these pioneering individuals recognised for their discovery. Take for example these historical medical discoveries:

The Discovery of the Stethoscope

René-Théophile-Hyacinthe Laennec (February 17, 1781 – August 13, 1826) was a French physician. He invented the stethoscope in 1816. Laennec is said to have seen schoolchildren playing with long, hollow sticks in the days leading up to his innovation. The children held their ear to one end of the stick while the opposite end was scratched with a pin, the stick transmitted and amplified the scratch. He believed a method to diagnose chest conditions was needed, particularly for stout individuals where direct auscultation to the chest was either inadequate or embarrassing, especially for his female patients. In February 1818, he presented

his findings in a talk at the Academie de Medecin, later publishing his findings in 1819. Not all doctors readily embraced the new stethoscope. Although the *New England Journal of Medicine* reported the invention of the stethoscope two years later, in 1821, **as late as 1885** a professor of medicine stated, "He that hath ears to hear, let him use his ears and not a stethoscope." Even the founder of the American Heart Association, L. A. Connor 1866 - 1950) carried a silk handkerchief with him to place on the wall of the chest for ear auscultation.

Sources: Wikipedia. Canadian Family Physican VOL 39: October 1993; p.2223-2224

Washing of Hands Prior to Childbirth

Ignaz Philipp Semmelweis (July 1, 1818 - August 13, 1865) was the Hungarian physician who demonstrated that puerperal fever (also known as "childbed fever") was contagious and that its incidence could be drastically reduced by enforcing appropriate hand-washing behavior by medical care-givers. He made this discovery in 1847 while working in the Maternity Department of the Vienna Lying-in Hospital. After testing a few hypotheses, he found that the number of cases was drastically reduced if the doctors washed their hands carefully before dealing with a pregnant woman. Risk was especially high if they had been in contact with corpses before they treated the women. The germ theory of disease had not yet been developed at the time. Thus, Semmelweis concluded that some unknown "cadaveric material" caused childbed fever.

He lectured publicly about his results in 1850, however, the reception by the medical community was cold, if not hostile. His observations went against the current scientific opinion of the time, which blamed diseases on an imbalance of the basic "humours" in the body. It was also argued that even if his findings were correct, washing one's hands each time before treating a pregnant woman, as Semmelweis advised, would be too much work. Nor were doctors eager to admit that they had caused so many deaths. Semmelweis spent 14 years developing his ideas and lobbying for their acceptance, culminating in a book he wrote in 1861. The book received poor reviews, and he responded with polemic. In 1865, he suffered a nervous breakdown and was committed to an insane asylum where he soon died from blood poisoning. **and he is now recognized as a pioneer of antiseptic policy and prevention of nosocomial disease.**"

Source: <http://inventors.about.com/library/inventors/blantiseptics.htm>

Link of Helicobacter Pylori Infection with Gastric Ulcers

Helicobacter pylori was first discovered in the stomachs of patients with gastritis and stomach ulcers in 1982 by Dr. **Barry Marshall and Dr. Robin Warren** of Perth, Western Australia. At the time the conventional thinking was that no bacterium can live in the human stomach as the stomach produced extensive amounts of acid of strength to the acid found in a car battery. German scientists found spiral-shaped bacteria in the lining of the human stomach as early as 1875, but they were unable to culture it and the results were eventually forgotten. Other researchers also observed bacteria in the stomach over the years. However interest in the bacteria waned when an American study published in 1954 failed to observe the bacteria

in 1180 stomach biopsies. In their original paper, Warren and Marshall contended that most stomach ulcers and gastritis were caused by infection by *Helicobacter pylori* and not by stress or spicy food as had been assumed before. There was skepticism by the medical community that *Helicobacter pylori* caused gastritis. In an attempt to prove the association Marshall took the radical step of drinking a beaker of *H. pylori* culture. He became ill with nausea and vomiting several days later. An endoscopy ten days after inoculation revealed signs of gastritis and the presence of *H. pylori*. These results suggested that *H. pylori* was the causative agent of gastritis. Marshall and Warren went on to demonstrate that antibiotics are effective in the treatment of many cases of gastritis. Marshall and Warren were finally recognised for their discovery and awarded the 2005 Nobel Prize in Physiology or Medicine. In 1994, the National Institutes of Health (USA) published an opinion stating that most recurrent duodenal and gastric ulcers were caused by *H. pylori* and recommended that antibiotics be included in the treatment regimen.

Source: Wikipedia.

There are plenty more examples

I am also reminded that it was not that long ago that autistic children were regarded as the product of "**refrigerator mother's**" by psychiatrists and psychologists. Who would dare to stand up in public today and make the same claims?

I will make one thing clear - **not all children respond to dietary modification, nor is it advocated as the primary treatment**. Autism needs a multidisciplinary approach to achieve the best results. Also initial guidance by an experienced practitioner is highly recommended to ensure it is correctly implemented.